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ABSTRACT

This handbook attempts to answer questions about informal caregiving and caregivers, focusing on the rural elderly. The first section presents a national perspective on caregiving. Recipients of caregiving, providers of caregiving, the caregiving dilemma, and psychological, physical, family, and financial issues are discussed. The second section focuses on the rural factor. The third section discusses services used by caregivers, including home maintenance, homemaking, transportation, nursing services, personal care, companion services, adult day care, etc. The fourth section discusses potential solutions to service problems. The fifth section discusses caregiver supports and focuses on respite care. The sixth section discusses support groups for family caregivers, noting that support groups which do work in rural areas tend to focus on education and less on support with personal concerns. This section also discusses the role of education programs for caregivers. The seventh section examines the caregiving issue as a family issue and describes research needs. Appendices include an Education and Training Resources Manuals list (9 items) and a Caregiver Bibliography of approximately 130 items. (Contains 20 general references.) (ABL)

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CAREGIVING FOR FRAIL ELDERS

IN

RURAL AMERICA

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CAREGIVING FOR FRAIL ELDERS IN RURAL AMERICA

INTRODUCTION

Caregiving of elders is as old as humankind itself. It is not a new phenomenon. Caregiving in some form or manner has been an integral part of every society throughout history, ranging from the earliest and most primitive to the most recent and complex. The first and last years of every human life require some kind of care from those who are better able and in control of the environment.

A great deal of recent discussion and attention has identified caregiving as one of the major concerns of the rural aging network. Books, publications, national and local media are increasingly giving coverage to such topics as the family caregiver and caregivers in the workplace. Caregiving topics are frequently addressed at aging conferences and workshops. Yet there are many questions and misconceptions about informal caregiving and caregivers, particularly when the rural factor is added to the overall picture. In this handbook we hope to answer some of these questions and shed light on some of the misconceptions about the state of caregiving in Rural America.

At present, there is a tendency to idealize "The old days when families took care of their own." However, from the colonial era up through the 1960's laws were enacted to require that adult children provide some financial support for their aging parents. Over the last 60 years there has been a shift in the responsibility from the family as the primary support to a combination of family and public support, yet there is no evidence that families are ultimately less helpful to their elders than in the past. Many of the means by which help is given have changed, but family caregivers are still the core element of what is referred to as informal care. Such informal care is that which is provided outside of formal organizational, governmental or institutional systems and such caregivers provide the vast bulk of the help needed by frail elderly persons. Indeed, the formal system could not handle the numbers of persons seeking assistance should the informal system not be there.

THE NATIONAL PERSPECTIVE

WHAT IS CAREGIVING?

Caring is one's feeling of concern for another. Caregiving demonstrates one's commitment to the welfare of another by making behavioral expression of that commitment. For most people there are many relationships in which there is an ordinary exchange of assistance. There is a point that cannot be clearly defined when this assistance goes beyond the ordinary and is unequal in distribution. In relationship to aging parents there may be a time when impairment leads to increasing dependency. This dependency often leads to changes in the life of each person in the relationship as well as changes within the relationship. Caregiving is a term that is used in the field of aging to describe a wide range of support that is provided those elders who experience limitations in one or more tasks of daily living. At one end of the continuum, this care may be a family member providing transportation to and from doctors appointments or to do shopping. It can extend to helping with housecleaning or the provision of occasional meals in situations where rural elders are still, for the most part, independent and caring for themselves. This caregiving continuum increases as the amount of care provided by family and friends increases. At the other end, care may consist of bathing, feeding, carrying, that is, coping with almost full dependency.

We know that there are many different motivations for those who choose to care for an elderly parent or another older family member, friend or neighbor (Jarrett, 1985). Although it may seem out of step with our somewhat cynical times, the motivation for many is as simple as love. Similarly, the impetus may come from a family tradition or a deep-seated respect for older persons as elders of the family or community. Others may be motivated more by a sense of equity. They return care as a just repayment for care they received from their parents or others. Many feel that they can simply provide better quality care than could a nursing home. For yet others the motivator is a severe case of guilt or the fear of condemnation by the community for neglecting a parent. In some cases the prospect of financial gain or the fear of emotional or physical violence from the elder can be powerful motivators.

On the other hand, some families will choose not to provide direct care but use professional services, in or out of the home. There may be a history of poor personal interaction that would prevent the giving or the receiving of care. The family may not be able to provide the quality and/or quantity of care needed. Others simply cannot provide the time and space required to incorporate the rural elder into their home life.

THE RECIPIENTS OF CAREGIVING

Demographers tell us that the current average life expectancy for women is 78.7 years and for men is 71.2 years (Atchley, 1988). It is anticipated that by the year 2000, the life expectancy for women will increase to 81 years and 74.1 years for men. The number of older

persons in the United States is growing faster in proportion to the total population than younger age groups. In 1980 the percentage of the population 65 and over was 12.4 percent (30.4 million) and it is estimated that this will be 13 percent by 2030 (AARP, 1989).

Changes in public health and sanitation, medicines, and antibiotics have all contributed to the increased life expectancy of rural elders. As with urban and suburban elders, there has been much more rapid growth of the old-old segment, those 85 years of age and over. It is estimated that between 1984 and 2050 the 85- plus population will increase from 1 to 5 percent of the overall population. The 85 and older age group, the very age cohort that most needs caregiving, will double in size from 2.6 million today to 5.1 million by the year 2030.

This oldest age group is the population that is at greatest risk of chronic illness and has the greatest need for health and social services. Chronic disease, not surprisingly, is often a consequence of longer life span. Most of our population now dies of chronic illnesses as opposed to the early 1900's when people were more likely to die from a wide variety of acute illnesses. The majority of the elderly have at least one chronic illness with the average person having four after age 65. Chronic illness is significant as it is likely to affect the individual's ability to perform activities of daily living (ADL). In short, because people are now living longer they are more likely to have multiple illnesses which limit them. The recent development of shorter hospitalization policies and programs such as Diagnostic Related Group (DRG) are forcing a greater frail elderly population out of the institutional health care system, and requiring greater dependence upon other family or community support.

Given this data and the demographic trends, it is widely predicted that in the decade of the 90's the demand on family caregivers will at least double. Already, six million older people require assistance with an ADL such as: bathing, dressing, eating, transference in and out of bed/chair, mobility, toileting, cooking, housecleaning, laundry, and transportation. Thus, some 48 percent of those over 85 require assistance in one or more ADL.

Among other consequences of these population trends will be the increase in multi-generational families. One fifth of the people in their early sixties have a surviving parent, as do 10 percent in their late sixties and 3 percent in their seventies. The growth of the older population will force a larger percentage of the elderly population itself into the caregiver role.

THE PROVIDERS OF CAREGIVING

The increase in life expectancy since 1900 has been accompanied by a decrease in fertility in our country. This decrease in birth means that there are fewer children and siblings to share in the caregiver burden. For the first time in history the average married couple has more parents than children. The average couple has two children and four

parents. This does not account for the additional demands generated by the ever increasing numbers of stepchildren and stepparents.

Research clearly indicates that the family is committed to the care of its dependent members, old or young. A 1984 study indicated that 80 percent of those elders who lived alone and had children were in contact with the child, in person or by phone, at least once a week. Family caregivers provide 80-90 percent of medically related care, personal care, household maintenance, transportation, and shopping needed by those elders who cannot do these tasks for themselves.

Informal caregivers, as noted, primarily family, provide most long-term care (LTC). Of those elders with LTC needs, only 20 percent live in nursing homes. Family care has been shown to be one of the most critical factors in preventing or delaying institutionalization as those with family supports tend to enter nursing homes at much higher levels of impairment.

Informal caregivers are the major source of assistance for 80 percent of the frail elderly. The National Long-Term Care Survey and Informal Caregivers Survey (NLTC) (Stone, Cafferata, & Sangl 1987) found that 2.2 million caregivers aged 14 or older were providing unpaid assistance to 1.6 million noninstitutionalized disabled elderly persons. For those elderly needing some form of assistance from family or friends these activities range from personal care to household maintenance, shopping and transportation. Viewed from the perspective of most older persons, family members are the clear preference as the source of caregiving assistance. The extended family unit traditionally expends significant energy in meeting the social, psychological and physical needs of its elderly members. Approximately 44 percent of caregivers have been furnishing assistance for between one and five years, a fifth for five years or more. A disproportionate number of caregivers are low-income or live in poverty, and those who are employed are frequently in jobs with rigid schedules.

The same NLTC Survey (Stone, et al., 1987) found that 72 percent of caregivers were female, as opposed to 28 percent male. Of these female caregivers 44 percent were adult daughters caring for parents and 23 percent were giving care to a spouse. Although the average age of caregivers was 57.3 years, 31 percent of all caregivers were employed. Today 51 percent of American women work, many of them juggling work and caregiving with their personal needs and aspirations. Nine percent of working women report they left the labor force to be a primary caregiver.

Since caregivers are most likely to be in their 40's and 50's, they are often still caring for children when their parental caregiving begins. The NLTC Survey (Stone, et al., 1987) showed that 25 percent of children providing caregiving to an elder had children under 18 in the household. This has been called the "sandwich generation." Given the growth of the older population, recent studies have established that the American woman can expect to spend more years caring for an aging parent than for dependent children, with the average

woman spending 17 years caring for a child and 18 years caring for a parent. Although women may have been trained in caregiving skills by child-rearing, the dependency of children predictably decreases as they grow older. Care for the elderly is far less predictable and is likely to increase in dependency as it progresses.

The spouse of the frail elder is the most likely caregiver; next are adult daughters, then daughters-in-law, followed by sons and other relatives. Wives of impaired men provide the most informal care. Men lag behind women in caregiving but several initial surveys indicate that as many as 45 percent of males in our society also perform one or more caregiving functions for an older person. This type of care ranges from emotional support to shopping and cooking, transportation and banking aid as well as assistance with personal hygiene care, and transportation. As a sub theme of this growing phenomenon, adult children provide more care, and more difficult forms of care, over longer periods of time than did caregivers in the past. A study by the National Association of Area Agencies on Aging (National Association of Area Agencies on Aging, 1987) found that the typical caregiver is a 52 year-old married woman who provides 15.9 hours of care per week for a 76.6 year-old widowed mother or mother-in-law.

The divorce rate has also effected caregiving. There is a declining availability of spouses as caregivers and there is the additional difficulty of caring for divorced parents who are often geographically separated.

THE CAREGIVING DILEMMA

The time of caring for an older parent or relative can be one of joy and enrichment. It can be a period of increased sharing, a renewal of that special closeness that has perhaps slipped away over the years. It can be a time for the healing of those old wounds left festering from childhood or adolescence. It can be a time for renewing old friendships or gaining wisdom from an elder. The majority of caregivers actually report that providing care makes them feel useful. Many anecdotal reports attest to caregivers' satisfaction knowing that their older relative is receiving help while remaining in the community. For many caregivers the giving of assistance is not a one-way street. Rather it is part of a mutual aid pact, as approximately one-fourth of caregivers report that the older person for whom they care helps financially or with household chores.

The bulk of present research, however, presents a less positive picture of caregiving. For example, a study conducted by the Benjamin Rose Institute, (Deimling, Bass, & Jensen, 1987) found that four out of five caregivers indicated that some aspect of helping was difficult, tiring, or emotionally upsetting. Six out of ten said they had no clear idea about what was best to do in the caregiving situation, while more than half said the person they cared for made too many demands on them.

A clear solution to the problem wou'd seem to be provision of more training, support groups, and formal in-home services for caregivers. Yet long term effects of such programs

have often not been positive. Caregivers tend to remain independent, seeking assistance only when the situation has reached an impossible extreme. Often caregiver programs have not been effective in assisting caregivers before the burnout point is reached. Much of the caregiver research is based on those caregivers who are stressed to the point of reaching out to the formal system for some form of assistance. Planners, policymakers and trainers who seek to help caregivers need to analyze the research that is currently available in order to correct the direction of existing programs, develop new ones and stimulate further research in areas where there is a need for it appears. Involvement of caregivers themselves in program design is essential.

PSYCHOSOCIAL ISSUES

A pervasive theme of research centers on the burden and the stress of caregiving. The caregiving process can be a time of increased anxiety and difficulty, particularly when the responsibilities of working, marriage, child rearing and parental caregiving collide. When the demands of work, spouses and children are juxtaposed against those of an aging parent with many needs, severe emotional drain can occur. Some research even reports that although most caregivers feel "close" to their care receivers, an inverse correlation exists between the closeness of kin relationship and the ability to get along without rancor (Cantor, 1983). If there are prior family problems lurking in the background, such as abuse, neglect or denial of emotional or financial support, there can be a potentially dangerous situation because the caregiver which was abused now is in the position of power.

It is easy to assume that conflicting roles as worker, wife, mother, for example always increase stress. However, a study by Stoller and Pugliesi (1989) suggests otherwise. After reviewing the data of a variety of studies they suggest that these various roles can actually serve as an emotional resource for the caregiver, sometimes linking them to other social networks. Occupying multiple roles is actually associated with better health, lower psychological stress, higher self-esteem and greater well-being. There is a threshold, however, beyond which multiple roles become detrimental.

Both Stoller and Pugliesi (1989) and Brody (1985) point out that many of the stress-reported issues relate to aspects of either feeling totally responsible for caregiving or feeling guilty that not enough is being done for the care receiver. These aspects are as much related to individual patterns as well as family dynamics. In looking at issues of competing family obligations or feeling total responsibility, we must ask whether the caregiver really allows others to participate or help. Does the caregiver put himself in the role of super person and not let others know of needs or allow others to share in the responsibility? From the literature on helpers, both formal and informal, it appears that some caregivers run a very high risk of stress due to certain personality issues: there may be aspects of control and identifying as the caretaker that are a part of the individual's personality. Persons with these personality traits do not easily allow themselves to be helped. It seems clear that informal caregivers must be or become able to recognize and accept their own limitations and seek assistance when it is needed.

It is not surprising that interpersonal problems are frequently reported by caregivers. The pressures of parent care may reactivate family relationship problems. Dependency of the older person on an adult child is often difficult for both. There is little more than anecdotal information on how the care receiver responds to care, however the research does show strain for the caregiver. Brody (1985) relates this dependency problem to unresolved issues on the adult child's part, regarding his or her own dependency needs. The adult child may also attempt to relate this situation of caregiving to that of a parent caring for a child. It is Brody's (1985) contention that either case will lead to increasing frustration and guilt for the caregiver.

A study by Baila Miller (University of Illinois) found that each sex emphasized different aspects of control in the caregiving role; Miller states that men have had a more instrumental focus, concentrating on tasks, goals, and problem-solving. Women have been more person-oriented, concentrating on relationships, feelings, and the effects of their behavior on others. Although each approach has its pros and cons, the male approach may have advantages in the caregiving role. Men in this role focus on organizing the task at hand rather than on how their spouse is feeling. It is important to realize that affection is not a necessary condition for caregiving. Research confirms that what is necessary is an attitude of positive concern for the elder being served.

The aspects of caregiving that are reported as most stressful are caring for an incontinent elder and/or one suffering from dementia. It is the personal care, such as bathing that is most burdensome. The level of support given by other informal or formal caregivers is very important. Much of the stress reported relates to becoming time-restricted and adjusting to severely limited social interaction. Symptoms of depression, anxiety, feelings of helplessness, lowered morale and emotional exhaustion are quite commonly cited. Caregivers assisting Alzheimer's victims reported three times as many emotional stress symptoms as the general population. They are two to three times more likely than the person in the general population to take psychotropic drugs. Twelve percent admitted that they used alcohol as a way of coping with the strain.

Often the caregiver is faced with the clear decline of health and impending death of the person they care for, raising the issue of anticipatory grief. The closer the bond between caregiver and receiver, the more stressful the specter of death. It is far more difficult to deal with the decline and/or loss of one who is close than one whose state can be seen more objectively, as in the institutional setting. Regardless of how close the relationship, proximity to the death process may be more stressful to the informal caregiver than to one who, by training or experience, is better prepared for this eventuality.

The emotional well-being of the caregiver is important due to the effect it has on physical health and on the quality of communication and interaction. Many caregivers have difficulty getting away because they feel guilty or selfish, however research shows that by caring for themselves the caregiver will provide better care. Thus, breaks and significant

periods of respite for the caregiver are most important tools for maintaining the individual caregiver.

PHYSICAL ISSUES

The physical demands of caregiving can be as difficult as the emotional problems. Often there is back-breaking physical labor, the results of incontinence with which to contend or the manifestations of dementia with which to cope. Given these circumstances and others, it is often difficult to provide care over a long period. Even in the best of situations, family caregivers need emotional support and occasional respite. When the responsibilities of caregiving are combined with the demands of employment, the potential for stress on the individual caregiver can become genuinely dangerous to health and other family relationships. In the worst case scenario the employed caregiver may have to choose between career and family or between care for the elder and responding to the demands of other family members.

The caregiving role may well be a 24-hour job with unpredictable ups and downs that keep the caregiver in a crisis framework. This in itself is stressful and draining. It is important to look at what caregivers can do to support themselves physically. The stamina and energy which are necessary to provide care over an extended period of time require the caregiver to take care of his or her own physical health. It is often difficult for the caregiver to get enough rest. Fatigue can be a serious drain physically and mentally. People caring for a relative with Alzheimer's disease have particular difficulty in this area. One of the effects of the disease is that the older person stays awake at night and wanders. Structuring the environment and time of the older person and using a support network to give a break can be essential.

FAMILY ISSUES

The burden experienced by caregivers appears to be highly related to the number of informal social supports available from other family members. The family can thus be either a potential source of support or a cause for additional stress. Although family members may not share equally in the care of elderly persons, they are considered part of the caregiving network and, more importantly, are part of the decision-making network. Family members who are excused from caregiving responsibilities are still considered by both elderly persons and adult children to be part of the decision-making process regarding care arrangements (Couper & Sheehan, 1987).

It has been found that family support systems generally operate under the principle of substitution, in which family members are available in "serial order," rather than acting as a "shared-functioning unit." Thus the caregiving experience burns out first one, then another of a family unit unless they are wise enough to parcel out the tasks and provide one another with respite from the various duties. This assumes, of course, that there are others with whom to share the caregiving function in the first place.

Caregiving demands often conflict with family members' individual perceptions and expectations of life and their respective roles such as future plans, privacy, vacations, money and social life. Relationships among spouses, adult siblings, and across generations are strained as members compete for attention and time and can occasionally lead to the reactivation of old intra-family rivalries. Even stable family relationships and positive perceptions can become distorted as the demands of caregiving increase.

FINANCIAL ISSUES

The personal resources of both recipient and provider in a family caregiving situation may be seriously drained or devastated by prolonged need for care. Financial compensation for family caregivers may come from insurance or benefits of organizations the elder has belonged to, such as the Aid and Attendance Allowance from the Veterans Administration. Federal Child and Dependent Care Credit provides limited tax credit and some state programs reimburse family members for care, again in a very limited fashion. Decreases in funding and increased utilization lead many agencies to direct their services toward private pay clients, making these services even less available to those with low income.

THE RURAL FACTOR

Rural living is often portrayed as easy-going and free from pressure. However, if one looks at what has happened to the farm economy over the last 30 years, one sees an increase in factors causing stress. The 1980's have seen an increase of oil prices affecting the price of fuel, fertilizer, herbicides, and other materials. Interest rates have increased. Foreign markets have decreased. Bumper crops have brought down prices. Farm, ranch, and small town families have been deeply impacted by these factors. This affects the financial resources available as well as time, emotional strength, and community resources, since they are affected by the economy of the community.

There is still a tendency to portray rural America as the idyllic place where family and neighbors all help one another. There are communities, rural and urban, where this is the case, but there are far more where this is the exception. For a variety of reasons there are those who do not want family and neighbors involved in their lives. These individuals may respond better to a neutral social service agency or choose to "go it alone."

Older rural people, by almost all economic, health, and social indicators, are poorer and less healthy; they have poorer housing, fewer options in personal and public transportation, and significantly more limited access to health professionals and to community-based programs and services (Coward & Lee, 1985). A significant difference exists between the informal support systems of the rural elderly and urban elderly. Research demonstrates that residential location is an important variable in the health status of older people. Nearly one in four of all elderly people live in non-metropolitan areas with the number in rural areas increasing. Despite the fact that the rural elderly report more chronic illness and physical impairment than their urban counterparts, the availability of formal services, health professionals and other practitioners is typically less available in rural areas. This disparity in services contributes to the stress and burden experienced by caregivers of rural elders, contributing to their need to turn to outside family resources when they deplete their own physical and emotional resources, or experience extreme stress. There have been many factors that have changed the social support networks available in rural areas decreasing their size and availability. The availability of adequate support networks of friends and family are an important factor in the primary caregiver being able to cope.

Providing service, both formal and informal, often requires sensitivity to the challenges of rural service delivery. The geography of the rural area itself my include barriers such as, mountains, desert, extreme cold, extreme heat, vast distances, and poor roads. The economy of the area as well as the availability of trained service providers, and the numbers of people that need and/or would use a service contribute to rural caregivers finding themselves more isolated and lacking more support services than the urban caregiver.

There is also a rural tradition of independence that tends to further isolate both rural elderly and their caregivers. The rural elderly use more informal helpers (Coward, Cutler & Mullens, 1990) and fewer paid helpers provide help with fewer instrumental activities of

daily living (Dwyer & Miller, 1990). This may reflect rural values, however it also reflects limited availability of formal services.

More rural elderly tend to be married and living with a spouse than urban elderly. There are fewer widows among the rural elderly when compared to urban elderly, however the widowed make up a large proportion of the rural elderly population, and the rural widowed rely more on relatives for aid than do rural married individuals (Coward, 1991). The children of these rural widows and widowers provide emotional support, advice, and transportation, yet fewer children are readily accessible in rural as contrasted to urban areas. Studies indicate that the strongest predictor of quality of relationship with children of the rural elderly is geographic proximity.

Farm residents have greater proximity and interaction with children and grandchildren than rural non-farm residents and urban residents. The farm advantage is particularly evident among men, indicating that instrumental ties, probably involving access to land, frequently link the male members of adjacent generations of farm families. The children of rural non-farm residents are most likely to have moved some distance away from their parents, minimizing opportunities for interaction. Residents of large cities are most likely to have at least one child residing within a ten-mile radius.

Rural couples generally have traditional attitudes regarding family roles (Dorfman & Heckert, 1988) and the division of labor. Women are responsible for the household functions such as cleaning and cooking, while men are responsible for financial functions of earning income and paying bills. This division of labor can cause difficulty if a spouse is in the caregiving role and is unprepared in handling some of the basic tasks such as balancing a checkbook or fixing meals.

Service providers often find that rural elderly resist formal services because they want to avoid getting caught up in a bureaucracy and perhaps lose some control over their life. They prefer to pick and choose the services that are important to them based on their values. In the caregiving and receiving system, the rural elderly value opportunities to participate and exchange service. A rural elderly care receiver will appreciate opportunities to take on some task that will support the caregiver.

The rural elderly that are comfortable with accepting assistance from friends and neighbors set boundaries as to what amount of assistance is acceptable. They generally are more comfortable if there has been some ongoing reciprocal relationship where they had been of assistance. Older persons who are new to the area may find it difficult since these reciprocal relationships have been built over lifetimes.

SERVICES USED BY CAREGIVERS

Most of the aging service delivery system is focused on the delivery of service directly to the older person. When agencies look at how much care is provided by the informal system of family and friends they should find justification for including the caregiver in their client base. This is not easy, since most funding is limited to services provided to the older person. The hesitancy of caregivers to seek and take advantage of services further complicates the issue. However, since there is evidence that many older persons are institutionalized due to the burnout of caregivers, we must do all we can to support them.

A study done by the National Association of Area Agencies on Aging (National Association of Area Agencies on Aging, 1987) found the following:

1. Sixty-five percent of all caregivers have used at least one support service.

2. Caregivers most frequently seek services which provide them with additional information or help with housework.

3. Service providers vary by type of service. However, assistance is most likely to come from community agencies, followed by friends and family.

4. Paid services are used primarily for home health aides or homemakers.

The following chart identifies usage of specific services.

Type of Help used by Caregivers	Percentage
Home Maintenance	53
Homemaking	52
Transportation	48
Nursing Services	44
Personal Care	40
Companion Services	32
Adult Day Care	23
Home Delivered Meals	23
Telephone Monitoring	20
Counseling	18
Miscellaneous	19

National Association of Area Agencies on Aging, 1987.

Much of the assistance that caregivers receive from the formal care system, such as on-site visits from home care workers, runs a high risk of being inadequate, even detrimental. Home care workers are generally low-paid, inadequately trained, and show a high rate of turnover. More than 60 percent of the aides employed by home health agencies leave before the end of a year. All of this makes it difficult for the caregiver to build a relationship of trust with the formal system, thus increasing his or her isolation.

Surveys found that the majority of caregivers do know what services are available. They found that caregivers do not recognize their own needs for services. Caregivers tend to feel that they should not seek services until they reach a crisis point. Barriers stop caregivers from using services. These barriers include: fear of agency control; reluctance to relinquish care to a stranger; difficulty in accessing the service due to scheduling, planning and preparing; and distaste for the label of the service.

Service providers must address these barriers in order to provide caregiver support. Caregivers need to know that their loved one will be well taken care of and are concerned about the policies for neglect and mismanaged care. Service providers need to build a relationship with the caregiver in order to be trusted. This will also help to reduce any guilt the caregiver may experience due to leaving the care receiver.

There is also concern on the caregiver's part about the care receiver's response to "an outsider" and/or their resistance to going to a service. Some caregivers allow the care receiver to make the choice of what services to use even when the care receiver is no longer mentally and emotionally capable of clear thinking. The caregiver's role loss, embarrassment about the care receiver's behavior, as well as a concern that their own skills in caregiving may be found lacking also contribute to the resistance to service usage.

It is important to provide support for caregivers; too often the focus is on getting caregivers to use a service rather than on making services useful to caregivers. Flexibility and caregiver control are important elements in making services accessible to the caregiver. In essence, caregivers want information, reassurance, communication, understanding and flexibility.

TOWARD SOLUTIONS

The provider of services to the rural elderly faces many challenges. These challenges can be used as an excuse for not providing service or as an opportunity to design services that are tailored to address these challenges. This begins with the service providers concept of a continuum of care and service. Allowing for the uniqueness of each situation to be taken into account as well as similarities. Creating a system that allows the caregiver maximum freedom and flexibility to enter and leave the support system using those services that they view as useful. Caregivers confront not only the caregiving task but the interpersonal ties and traditions. When services are brought into the home they are brought into a culture that is dynamic, changing and has both strengths and weaknesses. Support should be given in the least restrictive manner. Many services are marketed to the caregiver from a negative point of view. They emphasize the "burden" rather than the caregiving relationship. It is important to allow the caregiver himself to define his/her experience. Caregiving can be a burden and at the same time an achievement.

To address the needs of caregivers of frail rural elderly it is tempting to try to replicate urban caregiver models. Many of these models have not necessarily been objectively evaluated as to their long term success. Most caregiver support services have some difficulty getting caregivers to use them. All the more reason for the rural service provider to allow themselves to take the opportunity to assess the unique needs of the caregivers in their local and create a solution that is supportive of the rural caregiver based on the rural caregivers input. Many of the models that are prevalent in urban settings are developed based on those caregivers that have reached out to the social service delivery system. The majority of caregivers do not become a part of this system and are seldom a part of research or evaluation of programs. These programs are also designed to address the needs that service providers view as important and do not necessarily represent the caregivers perspective. Ideally services support the caregiver rather than displace them.

The rural community may be so small and have very few clients at anyone time making a full scale program less viable. Services designed to assist caregivers may be similar to those already available or needed by another population, e.g. visiting nurses and support groups are both services that are used by many age groups. If these services already exist they can be adapted to fit the needs of the caregiver.

Making sure that these services are accessible and flexible is essential. The language used to describe programs is often a barrier. The average person does not use terms such as "respite and adult day care." Making services available to address short-term and emergency needs will increase caregiver usage.

It is essential in the rural community that service providers are creative in facilitating the integration of family and friends into the care system. Some rural communities have developed cooperative agreements with urban areas to improve the level of service provision. This is particularly useful in sharing technology and a trained labor pool.

A service provider needs to assess the need for caregiver services. It is important to involve caregivers in this process. Inviting caregivers to serve on an advisory board may provide this input. Since time to attend meetings may be scarce for a caregiver, allowing for their participation via letter, telephone or conference calls may be necessary.

Given the individual nature of each caregiving situation and the sparse population in rural areas it may not be appropriate to develop caregiving programs. It may be more beneficial to look at all the services provided and see that they are caregiver friendly and that information and referral services include information on support for the caregiver. A telephone reassurance program or friendly visitor program can have a component that is directed to caregivers. In many communities this component may be used sporadically but the service would still be available. In rural communities caregiver programs usually need to be developed on a small scale and be flexible.

Service providers may have a concern that caregivers will relinquish their role and thus burden the service delivery system. Perhaps the essential service to be provided is that of consultation so that caregivers have an opportunity to assess their needs, become aware of services available, and be assisted in developing a cohesive plan of care that takes into account both the needs of the caregiver and the care recipient. A study done by the Family Survival Project, San Francisco (Enright & Friss, 1987), found that families who receive help from a resource and assessment agency, do not drop out of care but actually increase their participation while reducing their reliance on formal programs. The report found that the greatest need among caregivers was for respite and emotional support. Staff most often recommended family consultation and planning to enable caregivers to cope.

There are many opportunities for creative programming in serving rural caregivers. If your agency has a newsletter you may have a column allocated for caregivers to use to exchange helpful information. Through newsletters and educational programs you can inform caregivers on how to use services both private and public and where to find information and resources. Libraries and schools can be encouraged to make information available and be on the lookout for resources. Some agencies have provided instructional videos available for loan. Support groups may be formed which encourage caregivers to discuss issues with others who have had similar situations.

Often rural service providers themselves can be overwhelmed by caregivers, particularly when they are in an isolated rural area that does not have enough of a population base for a full scale caregiver support program. Service providers may often feel they are not doing enough. It is important to remember that caregivers calling for assistance may be in a siege mentality, responding emotionally and not logically to the challenge of the moment, or exploding from the buildup of pressure. Having someone who will listen, help them organize their thinking and reassure them is a real service. The three most essential actions a service provider can take on behalf of the caregiver are: 1. Listen, 2. Refer: to education/information and resource persons/services, 3. Follow-up: provide support for the caregiver to express their own solutions.

TRADITIONAL CAREGIVER SUPPORT

There are some hopeful developments in dealing with the caregiver dilemma. The growth of respite care services, and the development of new education and training programs are a real encouragement. There are also several creative and productive model programs that planners and providers can look to for guidance as they seek to initiate or improve caregiver programs.

RESPITE CARE

Respite care is the term used for a service that provides an opportunity for relief from caregiving so that the caregiver can remain healthy and continue in the caregiving role. This is usually thought of as creating an opportunity for the caregiver to take a break from caregiving for vacations, emergencies, personal business, employment, or social activities. Both time to take care of household business and time for relaxation and socialization are very important for the replenishment of the caregiver on a physical, mental and emotional level. Caregivers have often become so identified with their role that it is difficult for them to leave this role for even a short period of time. It is important to work with the caregiver to provide services in such a manner that the caregiver can leave their loved one in the care of another without undue guilt and anxiety.

In the very early stages of caregiving there is generally no need for respite care as the time consumed by caregiving is a small portion of the individual's activities. Those caring for someone very frail and in the last stage of life are generally not inclined to leave the person they are caring for. An older person in this condition is also more likely to have been placed in an institutional setting if the family is not able to provide the level of care needed. It is the vast number of caregivers that fall between these extremes who need respite services.

Short-term respite service may be few hours or all day and may be provided through in-home paid service, volunteers, or adult day care. Long-term respite is overnight, weekend or longer. This may be provided in the home, again by paid service or volunteer help, or in a nursing facility. Most caregivers want affordable short-term, in-home care. Long-term care is important however, particularly for emergencies. There are four models of respite care: in-home care, short-term institutional care, adult day care, and emergency respite care.

In-home respite care involves someone coming to the residence of the care-receiver. This may be a network of family and friends that do so on an informal basis. It may also be a service provided by a community organization that provides paid or volunteer staff for such a purpose. In either case it is essential that those providing respite be given some basic orientation to the physical and emotional needs of the person they are caring for, as well as appropriate response in an emergency situation. In-home respite care often works best if the respite worker/volunteer is able to come several times to work with the caregiver before the caregiver leaves them on their own. This helps both parties but particularly the

caregiver who is reticent to leave their loved one. This provides an opportunity to get comfortable and get to know each other as well as allow the caregiver to do some "custom" training.

Short-term institutional care is generally provided by a nursing home. Many nursing homes provide an opportunity for an individual to be placed in the facility for a short-term stay that may range from 24 hours to several weeks. This type of service is particularly useful when families have a need to leave the community for a short time. The caregiver does need to make arrangements for this service in advance and it may be costly. It is also important to take into account the condition of the care-receiver, as moving from one location to another can be very disruptive and uncomfortable for them.

Adult day care is a service that provides respite during the day at a location to which the elderly client can be taken. Adult day care services are sometimes restricted as to the type of client they are prepared to serve. The level of physical limitation, mental impairment, and care needed are factors that this service provider needs to be sure they are equipped to manage.

Emergency respite care is the least available of the respite care models. It provides for those situations in which a caregiver may find himself/herself where there is a need to have someone available to care for an elderly person on a short term basis, immediately. This can range from an emergency that calls for the caregiver to be gone from a few hours to a few days, usually without time to make arrangements.

In general, respite services are more available in urban than in rural settings. It is difficult to set up such a service unless there is a somewhat predictable need. The in-home respite service lends itself most readily to the rural setting. It is generally easier to transport a service provider to the client than to transport a frail client. Organizing and training a network of family and friends to provide respite on an as needed basis generally suites the needs of the rural community better than large scale programs that may go unused. Adult day care services are considered difficult to maintain in rural settings that have a small frail elderly population. There are programs and services that have been successful in rural areas. For further information on respite and adult day care see Day Care Programs and Services For Elders in Rural America, National Resource Center for Rural Elderly.

At times caregivers resist respite care. They have concern about letting their loved one be placed in an unknown situation. They may have a negative perception of formal services. Experience has shown a definite resistance of caregivers of the idea of taking a break. In offering respite care it is important to emphasize what the care recipient will gain, such as stimulation, companionship, and expansion of social network.

Rural caregivers often lack the resources of support services often available to urban caregivers. It is sometimes unfeasible to set up adult day care services in a rural area due to the large geographic area and limited number of clients at any given time. Respite care

also need to be very flexible. In rural areas bringing the resources to the individual's home is usually the best option. This leads to the need for a large number of informal supportive friends and family. In many cases volunteer programs such Volunteer Information Provider Program (Halpert & Sharp, 1988) have been very effective.

SUPPORT GROUPS

Support groups for family caregivers have become a popular offering. Support groups may be facilitated by the family caregivers themselves or may have a professional facilitator. In general, the purpose is for caregivers to have an opportunity to be with others who have had similar experiences. It provides an opportunity for understanding, companionship and sharing. Some support groups are primarily educational while others will focus on emotional support and yet others are a blend of educational, program and emotional support.

In many rural areas support groups do not work due to lack of interest, lack of numbers and lack of time. Those which do work tend to focus on education and less on support with personal concerns. There are many resources and models which can be adapted to the rural community, however it is important that caregivers themselves have expressed a desire for the support groups and are a part of its leadership. Due to the small numbers of caregivers within an area, the focus should be in a general caregiver support groups rather than one that is diagnosis specific.

In some communities it is not feasible to use support groups. However the principles of educational and emotional support can be accomplished in other ways such as newsletters, telephone and friendly visiting. These activities can be coordinated with existing programs such as clergy, extension homemaker clubs and Retired Senior Volunteer Program.

EDUCATION FOR CAREGIVERS

People are uncomfortable in their caregiving roles because they need training or because they feel that they need it. Sometimes very limited educational attention will do much to help them see and use their existing skills. For instance, it is a great help for many informal caregivers to realize that one of the essential skills for their role is that of managing the care being provided. This may include formal services as well as the assistance of family and friends.

Education programs need to be flexible in time and availability for caregivers to attend or to make arrangements for respite care to be provided. It is important to keep in mind that many of the caregivers will have been out of formal educational services for a long time and be hesitant to participate. Selecting educational styles that are oriented to building the caregivers' confidence along with their knowledge and skill base is essential.

There are a large number of caregiver education programs that have been developed and few of them have been specifically targeted to the rural caregiver. One program which was specifically developed for the rural caregiver is the Volunteer Information Provider Program, Center on Aging Studies, University of Missouri-Kansas City. Dr. Burton Halpert, one of the developers of this program, identified six key elements necessary to replicate this model. The six elements are: need, economy, community-based networks, educational

materials, training, and nurturing (Halpert & Sharp, 1988). It is useful to keep these six elements in mind when looking at educational programs you are considering for your unique community.

Programs which have been developed to educate and support caregivers have experienced difficulty in recruiting caregivers. Beyond the problems of being able to take time from their caregiving to attend such programs, it seems that most caregivers remain independent for as long as they can. It is for this reason that it would seem appropriate that more information/education be provided as a part of public media. If we look at public education about Osteoporosis, Alzheimer's, AIDS, we have evidence of the public becoming aware at very early stages of development of these issues. Why not an issue that seems to be a very natural part of family life? In the case of Alzheimer's this education has shown a marked positive effect on the caregiver. Providing information that leads to realistic expectations, problem-solving skills, and knowing what effects the disease has been demonstrated to decrease caregiver stress.

EDUCATIONAL RESOURCES

The Volunteer Information Provider Program is a strategy to reach and help rural family caregivers. This program developed at the University of Missouri-Kansas City (UMKC) was demonstrated in five rural Missouri counties and then replicated in over 20 states. This program capitalizes on two major community-based organizations in rural areas, Cooperative Extension Services and Extension Homemaker Clubs. Through Homemaker Clubs volunteers are recruited and trained in a "training the trainer" model to be information providers to caregivers in their community. The design of the program builds in coordination with area agencies on aging and the volunteers own social network to identify and support caregivers. Using this neighbor helping neighbor approach proved effective in rural communities.

Two additional resources developed at UMKC by the Center on Rural Elderly are: Directory of Education Programs for Caregivers of Elders and Reducing Barriers to Participation in Family Caregiving Training: Respite Options for Caregiver Training.

The directory is the result of one of the Center's primary activities, which has been to identify, catalog, and review programs in caregiver education, health education, and intergenerational relations. The directory contains cost, implementation, funding, evaluation, and contact information for each program included. A special effort was made to identify programs specifically developed for rural and minority audiences. Additionally, names and addresses of program reviewers, all interested in rural elders, will help expand the directory user's network of professional resources.

The manual addresses a major barrier to caregiver education: respite for the caregiver while s/he is attending caregiver training. The issue is particularly problematic because respite is less available in rural areas. This guide identifies ways caregiver trainers

can provide respite and offer come principles that will assist in the process. It contains a list of caregiver education programs, an extensive bibliography, and a list of "self-help" materials for caregivers. Contact:

Center on Aging
University of Missouri-Kansas City
5245 Rockhill Road
Kansas City, MO 64110-2499 (816) 235-1747

Another educational model designed to support the rural caregiver is the Senior Outreaching Seniors: SOS for Caregivers. this includes educational materials on such aging topics as, health care consumerism, stress, communication, legal issues and community resources to support those who care for seniors. The SOS is volume one of a seven-volume series developed by the Center on Rural Elderly. Contact:

Center on Rural Elderly
University Extension
426 Lewis Hall
University of Missouri-System
Columbia, MO 65211 (314) 882-1108

Parent Care is another excellent resource. It is a newsletter for professionals and families involved in caring for the elderly. Although Parent Care is no longer being published, back issues are available from:

Parent Care
The University of Kansas Gerontology Center
4089 Dole Human Development Center
Lawrence, KS 66045

FUTURE

The available research has focused primarily on the frail elders and their families. More research is needed which looks into the long-term role of caregiver, so strategies can be developed before crises occur. The caregiving issue should be looked at as a family issue. Family consultation and education would be able to address both the personal "caretaking" issues of the primary caretaker and facilitate healthier family interaction and support. Further support for caregivers might come from research on the majority of caregivers who successfully engage in this role. Identifying common characteristics, behaviors, and strategies would be an important basis for educational programs. Including family caregivers in the planning and design of programs which are designed to support them would seem obvious, yet it is seldom done. Since many of the stress related issues reported by caregivers are subject to the individual's interpretation, it would seem important to design stress management programs which help the caregiver to access their own mechanism rather than imposing artificial strategies.

Research on why caregivers do not use services when they are available is needed. It is important to identify the barriers to the use of services. More information specific to the rural caregiver is needed as well as information on the impact of ethnic and minority differences. For more ideas on the future of rural caregiving, "Rural Caregiving: Implications for the Aging Network" in The Future of Aging in Rural America: Proceedings of a National Symposium 1991 (Bull & Bane, Eds., 1992), is recommended.

REFERENCES

American Association of Retired Persons. (1989). A profile of older Americans. Washington, DC: Author.

Atchley, R.C. (1988). Social forces and aging (6th ed.). Belmont, CA: Wadsworth.

Brody, E.M. (1985). Parent care as a normative family stress. The Gerontologist, 25, 1, 19-29.

Bull, C.N., & Bane, S.D. (Eds.). The Future of Aging in rural America: Proceedings of a National Symposium 1991. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 597-604.

Couper, D. P., & Sheehan, N.W. (1987). Family dynamics for caregivers: An educational model. Family Relations, 36, 181-186.

Coward, R.T., & Dwyer, J.W. (1991). A handbook on health programs and services for elders in rural America. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Coward, R.T., & Lee, G. (1985). The elderly in rural society: Every fourth elderly. New York: Springer.

Coward, R.T., Cutler, S.J., & Mullens, (1990). Residential differences in the comparisons of the helping networks of impaired elders. Family Relations, 39, 44-50.

Deimling, G.T., Bass, D., & Jensen, C. (1987). Caregiving for the elderly: Recognizing your strengths and resources. Benjamin Rose Institute.

Dorfman, L., & Heckert, D. (1988). Egalitarianism in retired rural couples: Household tasks, decision making and leisure activities. Family Relations, 37, 73-78.

Dwyer, J.W., & Miller, M.K. (1990). Determinants of primary caregiver stress and burden: Area of residence and the caregiving networks of frail elders. The Journal of Rural Health, 6, 2, 161-184.

Enright, R.B., & Friss, L. (1987). Employed caregivers of brain impaired adults: An assessment of the dual role. San Francisco: Family Survival Project.

Halpert, B.P., & Sharp, T.S. (1988, November). A strategy to meet the needs of terminally ill elderly persons and their caregivers in rural communities. Paper presented at the Annual Meeting of the Gerontological Society of America, San Francisco, CA.

Heide, J., & Webb, L.C. (1991). Day care programs and services for elders in rural America. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Jarrett, W.H. (1985). Caregiving within kinship systems: Is affection really necessary? The Gerontologist, 25, 1, 5-10.

Miller, B. University of Illinois. Parent Care, 3, 3.

National Association of Area Agencies on Aging. (1987). Breadwinners and caregivers: Supporting workers who care for elderly family members. Washington, DC: Author.

Stoller, E.P., & Pugliesi, K.L. (1989). Other roles of caregivers: Competing responsibilities or supportive resources. Journal of Gerontology: Social Sciences, 44, 6 5231-238.

Stone, R., Cafferata, G.L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27, 5, 616-626.

APPENDIX A

Education and Training Resources
Manuals

Bane, S.D., & Halpert, B.P. (1988). The resource manual: Information for caregivers of the elderly. Kansas City: University of Missouri, Center on Aging Studies, 5245 Rockhill Rd., Kansas City, MO 64110-2499 (816) 235-2184.

Bane, S.D., & Halpert, B.P. (1988). The instructor's manual: Information for caregivers of the elderly. Kansas City: University of Missouri, Center on Aging Studies, 5245 Rockhill Rd., Kansas City, MO 64110-2499 (816) 235-2184.

Center on Rural Elderly. (1989). Directory of education programs for caregivers of elders. Kansas City: University of Missouri, Center on Aging Studies, 5245 Rockhill Rd., Kansas City, MO 64110-2499, (816) 235-2184.

Center on Rural Elderly. (1989). Reducing barriers to participation in family caregiver training: Respite options for caregiver training. Kansas City: University of Missouri, Center on Aging Studies, 5245 Rockhill Rd., Kansas City, MO 64110-2499 (816) 235-2184.

Corporate Eldercare: The aging network's response to the needs of employed caregivers. (1992). National Association of Area Agencies on Aging. Classes and Resource Center for caregivers. Suite 100, 1112 16th St., N.W., Washington, DC 20036, (202) 296-8130.

Henderson, J.N., Alexander, L.G., & Gutierrez-Mayka, M. (1990). Minority Alzheimer's caregivers: Removing barriers to community services. A training manual. Tampa: University of South Florida, National Resource Center on Alzheimer's Disease, Health Sciences Center.

Hilliard, M., Gibson, Leesa, & Livingston, L. Training the elderly and their caregivers in the home (TEACH): Nursing supervised training modules for caregivers of medically dependent frail elders (Award #90AM0139). Washington, DC: Administration on Aging, Office of Human Development Services.

National Association of Area Agencies on Aging. Classes and Resource Center for caregivers. Suite 100, 1112 16th St., N.W., Washington, DC 20036, (202) 296-8130.

Senior series: Extension programs for older adults. (1991). Columbia: University of Missouri, Center on Aging Studies, University Extension, 426 Lewis Hall, Columbia, MO 65211, (314) 882-1108.

The seven volumes include: Seniors outreaching seniors: SOS for caregivers (Volume 1). Enhancing self-care among the elderly (Volume 2). Nutrition education and the elderly (Volume 3). Intergenerational relations: Older adults and youth (Volume 4). Opportunities for expanding extension program (Volume 5). Radio and television (Volume 6). Senior olympics (Volume 7).

APPENDIX B

Caregivers Bibliography

Abou-Ghorra, I.M., Edgerton, J.W., Kenkel, M.B., Hargrove, D.S. & Heyman, S.R. (Eds.). (1990). Special issue: Aging in rural places [Special issue]. Journal of Rural Community Psychology, 11, 1.

Ambrogi, D., & London, C. (1985). Elder abuse laws: Their implications for caregivers. Generations, Fall, 37-39.

American Association of Retired Persons. (1986). Caregivers in the workplace: Survey results. Washington, DC: Author.

American Association of Retired Persons. (1987). A checklist of concerns/resources for caregivers. Washington, DC: Author.

American Association of Retired Persons. (1987). A handbook about care in the home. Washington, DC: Author.

American Association of Retired Persons. (1986). Making decisions for long term care. Washington, DC: Author.

American Association of Retired Persons. (1986). Miles away and still caring: A guide for long-distance caregivers. Washington, DC: Author.

American Association of Retired Persons. (1987). A profile of older Americans: 1987. Washington, DC: Author.

American Association of Retired Persons. (1988) Respite Guide. Washington, DC: Author.

American Association of Retired Persons. (1989). A profile of older Americans. Washington, DC: Author.

American Association of Retired Persons. (1989). Working caregivers report. Washington, DC: Author.

Bane, S.D., & Halpert, B.P. (1988). The resource manual: Information for caregivers of the elderly. Kansas City: University of Missouri, Center on Aging Studies.

Bane, S.D., & Halpert, B.P. (1988). The instructor's manual: Information for caregivers of the elderly. Kansas City: University of Missouri, Center on Aging Studies.

Barusch, A.S. (1988). Problems and coping strategies of elderly spouse caregivers. The Gerontologist, 28, 5, 677-685.

Barusch, A.S., & Spaid, W.M. (1989). Gender differences in caregiving: Why do wives report greater burden? The Gerontologist, 29, 5, 667-676.

Beam, V. (1983). A primer on hiring a home companion. Aging. 340, 12-14.

Biegel, D.E., & Blum, A. (1990). Aging and Caregiving: Theory, research and policy. Beverly Hills, CA: Sage.

Brody, E.M. (1985). Parent care as a normative family stress. The Gerontologist, 25, 1, 19-29.

Brody, E.M. (1985). "Women in the middle" and family help to older people. The Gerontologist, 21, 5, 471-480.

Brody, E.M., & Schoonover, C.B. (1986). Patterns of parent-care when adult daughters work and when they do not. The Gerontologist, 26, 4, 372-381.

Brody, E.M., Kleban, M.H., Johnsen, P.T., Hoffman, C., & Schoonover, C.B. (1987). Work status and parent care: A comparison of four groups of women. The Gerontologist, 27, 2, 201-208.

Bull, C.N., Howard, D.M., & Bane, S.D. (1991). Challenges and solutions to the provision of programs and services to rural elders. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Bull, C.N., & Bane, S.D. (1991). The future of aging in rural America: Proceedings of a national symposium. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Bureau of National Affairs. (1988). Employers and eldercare: A new benefit coming of age. The National Report on Work & Family. Special Report #3. Washington, DC: Bureau of National Affairs.

Bureau of National Affairs. (1988). 33 ways to ease work/family tensions - An employer's checklist. The National Report on Work & Family. Special Report #2. Washington, DC: Bureau of National Affairs.

Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23, 6, 597-604.

Cantor, M.H. (1985). Families: A basic source of long-term care for the elderly. Aging. 349, 8-13.

Carlin, V.F. Can mom live alone? (1991). Lexington, MA: Lexington/Heath.

Chapman, N., & Ebert, P. (1988). Taking steps to care: A resource guide for caregivers of elderly family members or friends. Oregon: Portland State University.

Clark, N.M., & Rakowski, W. (1983). Family caregivers of older adults: Improving helping skills. The Gerontologist, 23, 6, 637-642.

Couper, D.P., & Sheehan, N.W. (1987). Family dynamics for caregivers: An educational model. Family Relations, 36, 181-186.

Coward, R.T., & Smith, W.M., Jr. (1983). Family services: Issues and opportunities in contemporary rural America. Lincoln: University of Nebraska Press.

Coward, R.T., & Lee, G. (1985). The elderly in rural society: Every fourth elderly. New York: Springer.

Coward, R.T., & Cutler, S.J. (1989). Informal and formal health care systems for the rural elderly. Health Services Research, 23, 6.

Coward, R.T., Cutler, S.J., & Mullens, (1990). Residential differences in the comparisons of the helping networks of impaired elders. Family Relations, 39, 44-50.

Coward, R.T., & Dwyer, J.W. (1991). A handbook on health programs and services for elders in rural America. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Creedon, M.A., & Wagner, D.L. (1986). Eldercare: A resource guide. White Plains, NY: Pepsico, Inc.

Creedon, M.A. (1988). Elder care. Business & Economic Review. 34(2), 8-10.

Creedon, M.A. (Ed). (1987). Issues for an aging America: Employees and eldercare. Bridgeport, CT: University of Bridgeport.

Crichton, J. (1987). The age care sourcebook. New York: Simon & Schuster.

Cutler, L. (1985). Counseling caregivers. Generations, 10(1), 53-57.

Day, A.T. (1985). Who cares: Demographic trends challenge family care for the elderly (ISSN 0736-7716). Washington, DC: Population Reference Bureau, Inc.

Deimling, G.T., Bass, D., & Jensen, C. (1987). Caregiving for the elderly: Recognizing your strengths and resources. Benjamin Rose Institute.

Dorfman, L., & Heckert, D. (1988). Egalitarianism in retired rural couples: Household tasks, decision making and leisure activities. Family Relations, 37, 73-78.

Doty, P. (1986). Family care of the elderly: The role of public policy. The Millbank Quarterly, 64(1), 34-75.

Dwyer, J.W., & Miller, M.K. (1990). Determinants of primary caregiver stress and burden: Area of residence and the caregiving networks of frail elders. The Journal of Rural Health, 6, 2, 161-184.

Dwyer, J.W., & Miller, M.K. (1990). Differences in characteristics of the caregiving network by area of residence: Implications for primary caregiver stress and burden. Family Relations, 39, 27-37.

Dwyer, J.W., & Coward, R.T. (1990). The health status, health services utilization, and support networks of the rural elderly: A decade review. The Journal of Rural Health, 6, 4, 379-395.

Edinberg, M.A. (1987). Talking with your aging parents. Boston: Shambhala Publications.

Enright, R.B., & Friss, L. (1987). Employed caregivers of brain impaired adults: An assessment of the dual role. San Francisco: Family Survival Project.

Finley, N.J., Roberts, M.D., & Banahan, B.F. (1988). Motivators and inhibitors of attitudes of filial obligation toward aging parents. The Gerontologist, 28, 1,73-78.

Fitting, M., & Rabins, P. (1985). Men and women: Do they care differently? Generations, 10(1), 23-26.

Foyder, J.E. (1986). Family caregiver's guide. Cincinnati: The Futuro Co.

Fraser, V., & Thornton, S.M. (1987). Understanding "senility": A layperson's guide. Buffalo: Prometheus Books.

Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L.W. (1989). Prevalence of depression in family caregivers. The Gerontologist, 29, 4, 449-456.

Granovsky, N. (1989). Money talks for the sandwich generation. Nancy Granovsky, 205 C Special Services, College Station, TX 77843.

Greenberg, V.E. (1989). Your best is good enough: Aging parents and your emotions. New York: Lexington/MacMillian.

Greene, V.L., & Monahan, D.J. (1989). The effect of a support and education program on stress and burden among family caregivers to frail elderly persons. The Gerontologist, 29, 4, 472-477.

Haley, W.E. (1989). Group intervention for dementia family caregivers: A longitudinal perspective. The Gerontologist, 29, 4, 478-480.

Haemmerlie, F.M., & Montgomery, R.L. (1984). The homemaker needs of rural frail elderly from a client vs. agency perspective. Home Health Care Service Quarterly, 5(1), 61-73.

Halpert, B.P. (1988). Volunteer information provider program: A strategy to reach and help rural family caregivers. The Gerontologist, 28, 2, 256-259.

Halpert, B.P., & Sharp, T.S. (1989). A model to nationally replicate a locally successful rural family caregiver program: The volunteer information provider program. The Gerontologist, 29, 4, 561-563.

Hartford, M.E., & Parsons, R. (1989). Groups with relatives of dependent older adults. The Gerontologist, 22, 3, 394-398.

Hayslip, Jr. B., Ritter, M.L., Oltman, R.M., & McDonnell, C. (1980). Home care services and the rural elderly. The Gerontologist, 20, 2, 192-199.

Heide, J., & Webb, L.C. (1991). Day care programs and services for elders in rural America. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Home health care for the rural elderly: Experiences in Florida and Kentucky. (1982). Journal of Long Term Health Care, 1(2), 12-19.

Hooyman, N. (1986). Taking care: Supporting older people and their families.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist, 25, 6, 612-617.

Jarrett, W.H. (1985). Caregiving within kinship systems: Is affection really necessary? The Gerontologist, 25, 1, 5-10.

Johnson, C.L., & Catalano, D.J. (1983). A Longitudinal study of family supports to impaired elderly. The Gerontologist, 23, 6, 612-618.

Jones, P.S., & Golden, R.J. (Eds.). (1988). Special issue on family caregiving. Aging, No. 358.

Kane, R.A. (1985). A family caregiving policy: Should we have one? Generations, 10(1), 33-36.

Kinney, J.M., & Stephens, M.A.P. (1989). Caregiving hassles scale: Assessing the daily hassles of caring for a family member with dementia. The Gerontologist, 29, 3, 328-332.

Kivett, V.R. (1991). Informal supports among older rural minorities. Report prepared for the National Resource Center for Rural Elderly, University of Missouri-Kansas City.

Lawton,M.P., Brody, E.M., & Saperstein, A.R. (1989). A controlled study of respite service for caregivers of Alzheimer's patients. The Gerontologist, 29, 1, 8-16.

Levin, N.J. (1987). How to care for your parents: A handbook for adult children. Washington, DC: Storm King Press.

Lidoff, L. (1990). Caregiver support groups in America. Washington, DC: The National Council on the Aging.

Linsk, N.L., Keigher, S.M., & Osterbusch, S.E. (1988). States' policies regarding paid family caregiving. The Gerontologist, 28, 2, 204-212.

Lockery, S.A. (1985). Care in the minority family. Generations, 10(1), 27-29.

Lockery, S.A. (1991). Caregiving among racial and ethnic minority elders. Generations, 15(1), 58-62.

Mace, N.L., & Rabins, P.V. (1981). The 36-hour day: A family guide to caring for persons with Alzheimer's disease, related demential illness, and memory loss in later life. Baltimore: The Johns Hopkins University Press.

Mancini, J.A. (1989). Aging parents and adult children. Lexington, MA: Lexington/Heath.

Magnus, M. (Ed). (1988). Eldercare: Corporate awareness but little action. Personnel Journal, 67(6), 19 & 23.

Matthews, S. H., Werkner, J.E., & Delaney, P.J. (1989). Relative contributions of help by employed and nonemployed sisters to their elderly parents. Journals of Gerontology, 44, 1, S36-S44.

McGurrin, L. (1986). Should corporate benefits include helping with the care of elderly parents? New England Business, 8(14), 42 & 44.

McNulty, E.G. (1985). The dilemma of caring: For an older loved one or friend.

Meeker, S.E., & Campbell, N.D. (1986). Providing for dependent care. Business & Health, 3(7), 18-22.

Montgomery, R.J.V., & Borgatta, E.F. (1989). The effects of alternative support strategies on family caregiving. The Gerontologist, 29, 4, 457-464.

Motenko, A.K. (1989). The frustrations, gratifications, and well- being of dementia caregivers. The Gerontologist, 29, 2, 166-172.

Myers, Jane E. (1989). Adult children and aging parents. Dubuque, IA: Kendall/Hunt Publishing Co.

National Association of Area Agencies on Aging. (1987). Breadwinners and caregivers: Supporting workers who care for elderly family members. Washington, DC: Author.

National Council on the Aging. (1989). Respite resource guide. Washington, DC: Author.

Newhouse, J.K., & McAuley, W.J. (1987). Use of informal in-home care by rural elders. Family Relations, 36(4), 456-460.

Noelker, L.S., & Bass, D.M. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. The Journals of Gerontology, 44, 2, S63-S70.

Older Women's League. (1989). Failing America's caregivers: A status report on women who care. Author.

Owens, P. (1990). Barrier-free: Accessibility to the home for disabled persons. Dr. Peggy Owens, 205C Special Services, College Station, TX 77843.

Owens, P. (1989). Growing older: Self-help devices for daily living. Dr. Peggy Owens, 205C Special Services, College Station, TX 77843.

Patterson, S.L. (1987). Older rural natural helpers: Gender and site differences in the helping process. The Gerontologist, 27, 639.

Pegels, C.C. (1985). Our aging parents: A practical guide to elder care. Kolowalu Books.

Pratt, D., Schmall, V., & Wright, S. (1987). Ethical concerns of family caregivers to dementia patients. The Gerontologist, 27, 5, 631-638.

Pruchno, R.A., & Resch, N.L. (1989). Husbands and wives as care-givers: Antecedents of depression and burden. The Gerontologist, 29, 2, 159-165.

Quayhagen, M.P., & Quayhagen, M. (1988). Alzheimer's stress: Coping with the caregiving role. The Gerontologist, 28, 3, 391-396.

Rakowski, W., & Clark, N.M. (1985). Future outlook, caregiving, and care-receiving in the family context. The Gerontologist, 25, 6, 618-622.

Reever, K.E., & Thomas E. (1985). Training facilitators of self- help groups for caregivers to elders. Generations, 19, 1, 50-52.

Rosengarten, L. (1986). Creating a health-promoting group for elder couples on a home health care program. Social Work in Health Care, 11(4), 83-92.

Salamon, M.J. (1986). A basic guide to working with elders. Springer Publications.

Sankar, A. (1991). Ritual and dying: A cultural analysis of social support for caregivers. The Gerontologist, 31, 1, 43-50.

Scharlach, A.E. (1987). Role strain in mother-daughter relationships in later life. The Gerontologist, 27, 5, 627-631.

Sharp, T., Halpert, B.P., & Breytspraak, L.M. (1988). Impact of Medicare's prospective payment system and the farm crisis on the health care of the elderly: A case study. The Journal of Rural Health, 4(3).

Sheehan, N.W. (1987). The caregiver information project: Establishing an information network for family caregivers. Storrs: University of Connecticut.

Shelley, F.D. (1988). When your parents grow old. New York: Harper & Row.

Silliman, R.A., & Sternberg, J. (1988). Family Caregiving: Impact of patient functioning and underlying causes of dependency. The Gerontologist, 28, 3, 377-382.

Sommers, T. (1985). Caregiving: A woman's issue. Generations, 10(1), 9-13.

Spitze, G., & Logan, J. (1989). Gender differences in family support: Is there a payoff? The Gerontologist, 29, 1, 108-113.

Springer, Diane (1984). Family caregivers and the dependent elderly: Minimizing stress and maximizing independence. Beverly Hills: Sage.

Stoller, E.P., & Pugliesi, K.L. (1989). Other roles of caregivers: Competing responsibilities or supportive resources. Journal of Gerontology: Social Sciences, 44, 6, 5231-238.

Stone, R., Cafferata, G.L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist, 27, 5, 616-626.

Stone, R.I. (1991). Rural caregiving: Implications for the aging network. In C.N. Bull and S.D. Bane (Eds.) The future of aging in rural America: Proceedings of a national symposium. Kansas City: University of Missouri, National Resource Center for Rural Elderly.

Strain, L.A., & Chappell, N.L. (1984). Rural urban differences among adult day care participants in Manitoba. Canadian Journal of Aging, 2, 4, 197-209.

Tennstedt, S.L., McKinlay, J.B., & Sullivan, L.M. (1989). Informal care for frail elders: The role of secondary caregivers. The Gerontologist, 29, 5, 677-683.

Toseland, R.W., Rossiter, C.M., & Labrecque, M.S. (1989). The effectiveness of peer-led and professionally led groups to support family caregivers. The Gerontologist, 29, 4, 465-471.

Toseland, R.W., & Rossiter, C.M. (1989). Group interventions to support family caregivers: A review and analysis. The Gerontologist, 29, 4, 438-448.

True, N.B., & Wineman, J. (1989). Caregiving and retirement planning: A new partnership. Compensation & Benefits Management, 5, 4, 283-286.

Wasserman, A. (1983). A support group for the sandwich generation. Aging, 340, 2-4.

Warren, J. (1982). Adult sitter clinic (training). Ag Communications Bulletins, Room 101, TAMU, College Station, TX 77843-2112, (409) 845-1953.

Warren, J. (1983). Conflict with aging parents. Ag Communications Bulletins, Room 101, TAMU, College Station, TX 77843-2112, (409) 845-1953.

Warren, J. Family caregiver program series. Ag Communications Bulletins, Room 101, TAMU, College Station, TX 77843-2112, (409) 845-1953.

Warren, J. (1988). Preventing elder isolation and self-neglect. Ag Communications Bulletins, Room 101, TAMU, College Station, TX 77843-2112, (409) 845-1953.

Warren, J. (1985). Training respite caregivers for Alzheimer's family support. Ag Communications Bulletins, Room 101, TAMU, College Station, TX 77843-2112, (409) 845-1953.

Wiggins, E.S. (1983). Live-in help: A realistic option for dual career families. Aging, 340, 9-11.

Young, R.F., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. The Gerontologist, 29, 5, 660-666.

Zarit, S.H., & Toseland, R.W. (1989). Current and future direction in family caregiving research. The Gerontologist, 29, 4, 481-483.

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